

## Designing a national eye injury registry model for Iran

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### Peer-review Method

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### ABSTRACT

**Background:** The management of data related to eye injury can improve the process of care and treatment, and the implementation of preventive programs. The use of a national eye injury registry model greatly contributes to the management of eye injury data, prevention of these injuries, improvement of care, and cost control. **Objective:** This study aimed to propose a national eye injury registry model for Iran. **Methods:** This was an applied descriptive study. Based on a review of articles and information sources, and a comparative study of national eye injury registries in pioneering countries, a national eye injury registry model was designed for Iran. After confirming the reliability and validity of the questionnaire, the proposed model was given to ophthalmologists in a two-stage Delphi technique, and their comments were applied to the final model. **Results:** The proposed national eye injury registry model has six dimensions: goals, structure, data sources, minimum dataset, standards, and processes. **Conclusion:** As a registry is essential to the management of eye injury data, the proposed model can improve the management of the data flow between the cooperating organizations, facilitate the adoption of preventive strategies, and thus help reduce and prevent eye injury.

**Keywords:** eye injury; eye injury registry; registries

## 1. BACKGROUND

Eye injury is a highly prevalent cause of unilateral blindness, especially in developing countries (Khan et al., 2012). This type of injury causes disability and disrupts the lives of the affected people, while also having unjustifiable socioeconomic consequences for the healthcare system and the patients by incurring heavy treatment and rehabilitation costs (Soliman & Macky, 2008; Guerra Garcia et al., 2013). Due to the depth of this injury and the resulting disability, the prevention of eye injury should be a priority for all healthcare systems. Based on the global statistics on ocular injuries, The American Institute for the Prevention of Blindness estimates that 90% of these injuries are preventable (Serrano et al., 2003). Prevention strategies need knowledge of the cause of injury (May et al., 2000). Therefore, the systematic collection of standard data on the incidence of eye injury can help ophthalmologists in the successful prevention of these injuries (Kuhn et al., 2006). There should be a databank for recording and storing the cases of injury, reporting, following



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the patients, measuring the effectiveness of interventions, and planning and controlling the factors affecting the disease (Asadi & Paydar, 2018; Asadi et al., 2019; Sadeghi-Bazargani et al. 2019). The registry system is a component of the comprehensive disease management strategy that contributes to the organized care management support (Simon & Powers, 2004).

A registry provides this support and management through access to information and case finding processes, ensuring information quality, information analysis and reporting, and information management. In fact, a registry collects information that can be used for the gathering, management, and organization of specific information for a patient population. The data gathered by these systems enable comparison, analysis, and research on patient groups for information users (Schmidt et al., 2015). Without a comprehensive and valid registry and institutionalizing it in a country, it is impossible to develop prevention and continuous quality improvement (CQI) programs; estimate care and treatment costs; assess efficiency; conduct epidemiological research; perform decision-making, organization, and planning; examine the trend of incidence; identify at-risk populations; evaluate the effectiveness of prevention and intervention programs; or calculate the years lost due to disability (Iftikhar et al., 2019). Therefore, the need for preventing eye injury has led to the design and development of eye injury registry systems that identify the risk-factors in a defined population by collecting standard information and propose effective preventive and therapeutic measures based on effective planning and decision-making (Faal et al., 2010). Through this system, treatment techniques can be developed, improved, and made more effective. Eventually, by better understanding the mechanisms and conditions of the setting in which eye injury occurs, the effectiveness of injury prevention can be boosted (Parver, 1988). Various studies worldwide have emphasized the effective role of registry systems in reducing and preventing eye injury (Zaman et al., 2014; Abdelhak et al., 2014; Schmidt et al., 2015).

For instance, the United States Eye Injury Registry (USEIR) was formed in 1988. This national database collects information and shares it on a jointed database. The goal of this registry is to promote eye injury descriptive epidemiology, facilitate epidemiological research, collect data on treatment outcomes, and publish information on the prevention and management of eye injury in order to develop preventive strategies in society (ASOT, 2020). The case finding process in this registry is a review of patient records in inpatient and outpatient visits, the examination of patient visit results and medical reports, and reviewing the screening results (Kuhn et al., 2006). This registry utilizes a standard dataset for collecting and reporting eye injury, and employs the Ocular injury Score and Birmingham Eye Injury Terminology system for naming, defining, and classifying eye injury (Girkin et al., 2005). Moreover, the injuryRegister DGU was founded in Germany in 1993. This registry focuses on the epidemiology of the prevalence and features of eye injury on a national level (Trauma Register DGU, 2014). The data are collected from four sequential temporal phases of pre-clinic, emergency room and initial surgery, intensive care unit (ICU), and discharge, and are completed online in a minimum dataset (Trauma Register DGU®, 2020). To ensure the high-quality input of data, the acceptability of most parameters is checked when inputting the information. This includes the temporal sequence of the incidents and the following treatments, as well as the acceptability of vital parameters and laboratory results. The quality of data is continuously improved upon close cooperation between surgeons, data managers, and the information technology team (Trauma Register DGU®, 2014, Lustenberger & Lefering, 2020). Due to the pivotal role of national eye injury registry model in the management of eye injury data, the prevention of these injuries, the improvement of care, and cost control, and due to the necessity of a model for designing such a registry, the present study aimed to propose a national registry model for eye injury in Iran.

## 2. METHODOLOGY

The present applied descriptive study was conducted in three steps, explained below.

### Review of literature

To design the registry model, a review of the literature was performed by using laboratory sources, websites, and relevant sources in PubMed, Scopus, Embase, Wiley, and Science Direct, and by Then, expert opinions were applied to the proposed model. In the second step of the Delphi technique, an expert panel with six ophthalmologists and health information management experts was formed in order to finalize the proposed model. The registries of pioneering countries, including US, UK, Australia, Germany, and China, via eye injury, registry, and national eye injury registry keywords, from 2000 to date.

### Development of the proposed model for the national eye injury registry in Iran

In this stage, the national eye injury registry model for Iran was designed based on the review of articles and information sources, conducting a comparative study of national registries for eye injury in pioneering countries, and considering the status of eye injury in Iran and the involved organizations.

### Validation of the proposed model and provide of the final model

In this stage, the proposed model was developed in the form of a researcher-made questionnaire comprising questions based on the model dimensions. The questions had two options of “Agree” and “Disagree” with a blank space for suggestions. The questionnaire was given to 10 experts (six health information management experts and four ophthalmologists), and their opinions were sought for validity determination. Moreover, Cronbach's alpha was calculated to determine the reliability of the questionnaire. A Cronbach's alpha of  $> 0.7$  is acceptable in scientific domains. As this value turned out to be 94% in the present study, the validity of the questionnaire results was high. After the questionnaire's reliability and validity were confirmed, the proposed model was given to 20 experts ophthalmologists at Shahid Beheshti, Tehran, and Iran Universities of Medical Sciences and the Iranian Society of Ophthalmology with executive and organizational positions in addition to the care of patients. Expert opinions on the registry model were collected, and the agreement coefficient of 75% was set as the criterion for model acceptance. Then, expert opinions were applied to the proposed model. In the second step of the Delphi technique, an expert panel with six ophthalmologists and health information management experts was formed in order to finalize the proposed model.

## 3. RESULTS

The findings are presented in three categories.

### Results of the review of literature

The review of the literature showed that the most important processes in national eye injury registries include case finding, data gathering and abstraction, data quality control, processing, reporting, and patient follow-up. Moreover, the goals, structure, data sources, and minimum dataset of the registry should be clearly stated.

### Results of the proposed model for the national eye injury registry

List 1 presents this model and its main dimensions and processes.

**List 1** The proposed model for the national eye injury registry

Goals		Epidemiological study of eye injury Facilitating the comparison of the incidence rate of eye injury and its types on a national and international scale Assessing the quality of eye injury care and treatment outcomes Implementing and evaluating the effectiveness of eye injury prevention programs Developing and implementing an OTS system Resource planning and management
Data sources		Hospitals, clinics, doctors' offices, private ophthalmology centers, ocular research centers, emergency centers
Structure	Responding organization	The Department of Eye Health and Blindness Prevention at the Ministry of Health and Medical Education
	Organization method	Centralized
	Registry centers	Urban centers of the eye injury registry Provincial centers of the eye injury registry National center of the eye injury registry
	Cooperating organizations	State-run and private hospitals and clinics, registry centers, ophthalmology departments, The Iranian Society of Ophthalmology, ophthalmologists' offices, ophthalmology research centers, eye bank, The Iranian Nursing Organization, The State Welfare Organization, the Iranian Traffic Police, The Ministry of Cooperatives, Labor, and Social Welfare, The Ministry of

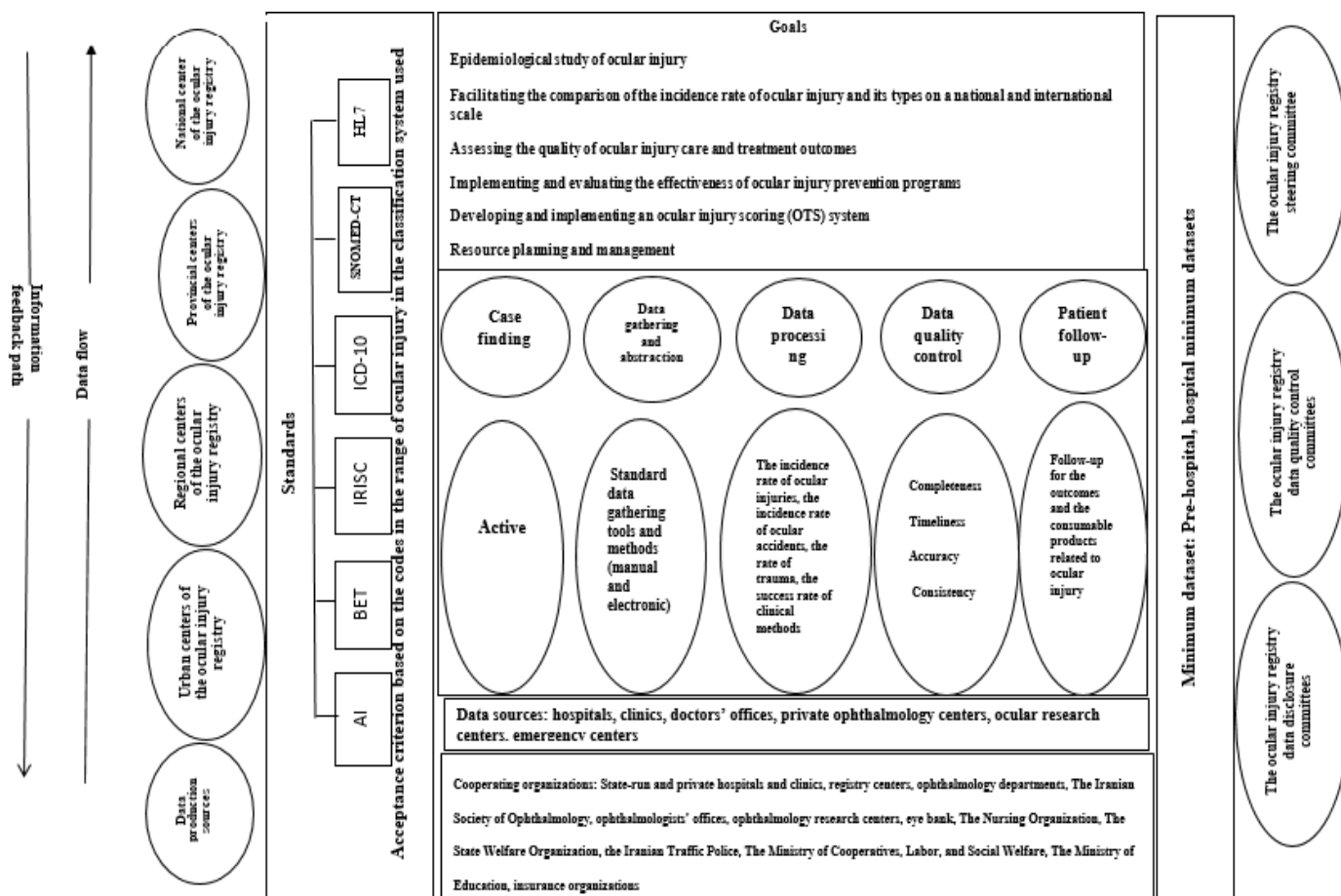
			Education, insurance organizations
	Supervisory committees	The eye injury registry data quality control committees The eye injury registry data disclosure committees The eye injury registry steering committee	
Minimum dataset		Pre-hospital dataset Patients' general information Location of injury Type of injury Visual status When the emergency department was contacted How the emergency department was notified of the incident Preliminary diagnosis Medical history Medical measures Hospital dataset Demographic data Clinical evaluation data Eye injury acuity and type Patients' medical history data Diagnostic data Treatment data Data related to the post-discharge outcome/complications Pattern of eye injury	
Standards	Terminology and classification system	ICD-10, BETT, RISC, AI	
	Nomenclature system	SNOMED-CT	
	Information exchange and messaging system	HL7	
Registry processes	Case finding	Active	
	Data gathering and abstraction	Based on the manual and electronic report form by the registry officials at the registry centers	
	Data quality	Quality control index	Completeness, timeliness, accuracy, consistency
		Quality control methods	Examining duplicates, mandatory data, and auditing the medical records of the patients
	Data processing	Eye injury ratio calculation Visual impairment and blindness ratio Prevalence of different types of eye injury Success rate of clinical methods and screening results Causes of injury Percentage of eye injury resulting from accidents Percentage of eye injury resulting from falling Percentage of optic nerve injury Processing the eye injury patterns	
	Reporting	Reporting method	Telephone calls Written reports

			Online reports
		Reporting period	Monthly - quarterly - semi-annual - annual
		Types of reports	Managerial, case finding, financial, and follow-up reports
	Patient follow-up	Goal of follow-up	Follow-up for outcomes of eye injury Follow-up for consumer products related to eye injury
		Follow-up methods	Telephone calls, sending reminder letters to patients, electronic communication (online)

OTS; OcularTruma scoring, BETT; Birmingham eye trauma terminology, ICD; International Statistical Classification of Diseases and Related Health Problems, AI; Abbreviated Injury, SNOMED-CT; Systematized Nomenclature of Medicine - Clinical Terms

### Results of the validation of the proposed model for the national eye injury registry

The opinions of experts on the validation of the model are given in Table 1, and the final model is displayed in Fig. 1.



**Figure 1** The model for the national eye injury registry in Iran

In the second stage of the Delphi technique, after applying the suggestions of the first stage and upon forming the expert panel, all the components of the model were confirmed by 100% of the experts.

## 4. DISCUSSION

As a major component of the healthcare system, registries provide information, thereby reducing healthcare costs and improving the healthcare provision processes (Hashemi et al., 2018). An important step in designing and developing registries is determining

their goals (Hoskin et al., 2019). In this study, as in other similar registries, the goals of the national eye injury registry included the epidemiology of eye injury, facilitating the comparison of the incidence rate of eye injury and its types on a national and international scale, assessing the quality of eye injury care and the treatment outcomes (ASOT, 2020; Trauma Register DGU®, 2014, Lustenberger & Lefering, 2020).

**Table 1** Summarized results of implementing the first stage of the Delphi technique

Expert agreement Percentage Examined components of the national registry	Agree	Disagree	Notes
Goals	100	0	–
Data sources	85	15	-
Registry structure	75	25	It was recommended that a regional center for eye injury be included in the structure.
Minimum dataset	85	15	-
Standards	100	0	It was suggested that the code acceptance criterion be added to the standards.
Registry processes	100	0	-

The most important processes considered in registries include case finding, data gathering and storage, data abstraction, patient follow-up, reporting, and data quality control (Asadi & Paydar, 2018; Asadi et al., 2019; Gliklich et al., 2014; Yao et al., 2016). Like other studies, the national eye injury registry model designed in the present study comprised the above-mentioned processes. Since a practical method for case finding is actively and automatically linking healthcare centers (ASOT, 2020; Kuhn & Morris, 2006), this process is performed in the present study actively and automatically. Moreover, in the proposed model, the data gathering process includes a network of eye injury registry centers at the city, province, region, and ministry level to provide access to precise information. Each of these centers cooperates in information collection, analysis, and feedback.

The minimum dataset is a valuable and comprehensive source for the continuous evaluation of recovery and planning. It also provides useful information for policy-makers, healthcare specialists, and stakeholders, eventually improving the quality of care and treatment and reducing the patient's length of stay at the hospital (Pati et al., 2019; Ahmadi et al., 2014). The existence of a minimum dataset is a major step in registry development as it reduces confusion in data collection and reporting (Palmer et al., 2013; Hawes et al., 1997). In the proposed model, the minimum dataset is divided into two sets: a pre-hospital dataset (to examine the causes of injury and location of incidents) and a hospital dataset (to collect and report eye injury information). The Ocular injury Score, SNOMED-CT, and Birmingham Eye injury Terminology are employed for the nomenclature, definition, and classification of eye injury (Girkin et al., 2005; Girkin et al., 2005; Feng et al., 2013). Furthermore, the acceptance criterion is based on the codes in the range of eye injury in the ICD-10 classification system (Beshay et al., 2017; Lee et al., 2015).

The eye injury registry plays a pivotal role in monitoring, development of clinical guidelines, and formation of eye injury prevention policies and strategies. The effectiveness of these registries is influenced by the quality of the information provided to users (Dudok & Hooper, 2012). The proposed method includes data quality dimensions such as completeness, timeliness, accuracy, and consistency, as well as quality control methods such as examining duplicates, mandatory data, and auditing the medical records of the patients. As for the quality and confidentiality of information, the formation of information control and disclosure committees in the registry is recommended. Moore and Clark emphasize that, as internal quality control and improvement tool, eye injury registry systems ensure the consistency, completeness, and precision of data over time, and are used for the support, revision, and determination of hospital processes; therefore, they require quality control to ensure data completeness, accuracy, and consistency (Moore & Clark, 2008; Hoskin et al., 2019).

In the present study, the goal of follow-up, follow-up for the eye injury outcomes, and follow-up for consumer products related to eye injury are recommended. In addition, different methods such as telephone calls, sending reminder letters to patients, and electronic communication (online) are included. According to Pollard et al., patient follow-up improves treatment processes, and sending text messages and reminder emails to patients and their families improves the follow-up process (Pollard et al., 2009). The

reporting feature is another important specification of registries. As the determination of processing indices is integral to the preparation of different reports, this factor plays a major role in drawing up reports for decision-making monitoring and improvement (Gliklich et al., 2014). The identification of indices and the reporting ability via different methods enhances the reporting feature for different groups and enables the comparison of data at different decision-making levels (CDC, 2020, Chiang et al., 2018). In the proposed model, based on different levels of decision-making and various users, different types of reports and reporting methods are suggested.

## 5. CONCLUSION

The existence of national eye injury registries greatly contributes to the management of eye injury data, thereby improving the quality of care and treatment and the development of prevention strategies for these injuries. For the accurate and standard implementation of such a registry, it is essential to have a comprehensive model that pays attention to different dimensions of design.

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### Conflict of interest

The authors declare that there are no conflicts of interests

### Contributors

Concept and study design: FA, NR; data collection: SA; analysis and interpretation: FA; Writing the article: FA, NR, SA; final approval of the article: FA.

### Data and materials availability

All data associated with this study are present in the paper.

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